

RESEARCH ARTICLE

Participation When Using Cognitive Assistive Devices – from the Perspective of People with Intellectual Disabilities

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Abstract

The aim of the study was to describe how people with intellectual disabilities experienced their participation in everyday activities when using cognitive assistive devices. The purpose of cognitive assistive devices is to compensate for cognitive problems, to enhance independence when performing activities and to support decision making in daily life. Nine persons, 17–37 years old, with mild intellectual disability were selected by purposive sampling. Data collection was conducted by semi-structured interviews. The results showed that participation in everyday activities increased when using cognitive assistive devices. The persons experienced having more control and health benefits using cognitive assistive devices in daily activities. There were participation restrictions related to attitudes from the social network towards participation, and attitudes towards the use of cognitive assistive devices from the persons themselves and from the social network. Occupational therapists should be aware of the social factors that may influence a client's participation in everyday activities when using cognitive assistive devices. There is a need for more research with clients with intellectual disabilities and further research concerning long-time use of cognitive assistive devices. Copyright © 2010 John Wiley & Sons, Ltd.

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Keywords

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Introduction

People with intellectual disabilities have difficulties in ordering and reordering information, in conducting action and thought processes and in using symbolism (Kylén, 1997). They also have a limited short-term memory (Kylén, 1997). The limitation of a short-term memory function affects the ability to receive and organize information. An adult person with a mild intellectual disability can often read and write but can have

difficulties in handling multi-faceted problems, finding alternative solutions and understanding possible situations (Kylén, 1997). The difficulty shows up, for example, in problems with planning daily activities, the perception of time and independently managing one's own finances. The consequences for the person do not only depend on their intellectual disability but also on what type of demands the environment puts on the person's abilities in each individual situation (SOU, 1976: 20).

The Swedish law concerning Support and Service for Persons with Certain Functional Impairments (LSS) (SFS, 1993: 387) states that people with intellectual disabilities should be able to influence their own lives. Further, the services they receive should include respect for self-determination and should support participation in social life. According to the Health and Medical Service Act (SFS, 1982: 763), a system has been established in Sweden to allow assistive devices to be assessed and prescribed to people with disabilities. The intention of prescribing an assistive device is to compensate for the impairment and to give better opportunities for participation (SOU, 2004: 83). However, the prescribing of cognitive assistive devices (CAD) to people with intellectual disabilities is a relatively new area. In Sweden, people with intellectual disabilities have been able to receive CAD prescribed since the middle of the 1990s. The aim of CAD is to increase independence in the performance of daily activities and create the opportunity to build a larger social network and participate more in important decision making (Jacobsson, 1999). CAD can support memory, planning, understanding and orientation (Lindström and Wennberg, 2004). The most commonly prescribed CADs are different types of time aids (Dahlberg, 2008).

The performance of activities is a result of a dynamic relationship between the person, the environment and the activity (Townsend, 2002). Having access to assistive devices may affect performance and participation. In order for assistive devices to be useful for the person and lead to increased participation, it is important to base prescription decisions on situations that the person himself has identified as a problem (Hammel et al., 2002). One of the important factors for successful usage of assistive devices is the support that the person receives from others (Reimer-Reiss and Wacker, 2000). The need for a supportive and positive attitude, a desire to give increased independence and control and an interest in new techniques are confirmed by studies (Arvidsson and Jonsson, 2006; Granlund et al., 1995; Hammel et al., 2002; Scherer, 2005).

According to the International Classification of Functioning, Disability and Health (WHO, 2001), assistive devices are categorized as an environmental factor, within the area of products and technique. The prescribing of assistive devices is one of the interventions that occupational therapists use to reach the goal of participation in meaningful life occupations (Kielhofner, 2008). A starting point in occupational

therapy is to base intervention on the person's requests and needs and ensure that interventions have a client-centred perspective (Townsend, 2002, Kielhofner, 2008).

A literature review regarding factors related to self-rated participation in persons with mild intellectual disability has been published by Arvidsson et al. (2008). Kjellberg (2002) studied how people with learning disabilities experience their opportunity to participate in decisions in leisure and work.

Arvidsson and Jonsson (2006) described how 'time aids' affected the independence and autonomy of adults with intellectual disability.

Thus, the purpose of this study is to describe experiences of participation when using CAD in daily activities from the perspective of people with intellectual disabilities. Participation was defined as having opportunities to influence, have control and make decisions in everyday life related to the use of cognitive assistive devices.

Method

Participants

A purposive sampling (Patton, 2002) was used. Inclusion criteria for those participating in the study were that they should have mild intellectual disability and be able to communicate verbally. The study focused on a young group of people between the ages of 17–37 years. Additionally, they needed to have been prescribed CAD within the last 2 years. Seven occupational therapists working in the area were informed via professional conferences, email and telephone about the study and asked to relay an easy-to-read letter with information to potential participants.

Two men and seven women agreed to participate in the study. Four of the participants lived with their parents, four lived in their own apartment with support from staff and one participant lived independently in an apartment. Five participants worked at a daily activity centre, two were at school and two were waiting to get a job. The most frequently used CAD was a handheld computer, Handi (Handitek, 2009) (Handitek AB, Rättvik, Sweden), with a specially developed program for time planning and support to manage money. A few of the participants had timers that counted down time, Time Rule (Westerstrand, 2009) (Westerstrands Urfabrik AB, Töreboda, Sweden) and weekly schedules (Table I).

Table I. Cognitive assistive devices related to person, age and sex

Person	Age	Sex	Prescribed cognitive assistive device	Use at the time of the interview
Anne	17	Female	Time Rule Handi	Only Time Rule
Barbara	23	Female	Handi	Yes
David	33	Male	Handi	Yes
Eve	21	Female	Handi	Yes
Fanny	23	Female	Handi	Yes
Gisela	37	Female	Handi	Yes
Helena	22	Female	Handi	Yes
Iris	30	Female	Handi	Yes
John	17	Male	Handi Week schedule	Yes

Both the Handi and the Time Rule make time visual using the same principle, i.e. time is shown by a number of dots. The dots provide a visual countdown as time goes by and when the time is up there is a beep. The Handi also shows what to do every day by means of text and pictures, and it has a synthesized voice that gives information. The Time Rule is a timer divided into four different selectable time intervals. The weekly schedule is a plasticized paper showing all the days of the week in columns. There is also a column for the hours. Each day has its own colour to make it easier to separate the days. On the weekly schedule, there are opportunities to write down what to do each day and what time these activities will be done (Table II).

The participants had been using their CADs for periods ranging from 1.5 months to 2 years (mean 7.9 months).

Ethical considerations

The local ethics committees approved the study, and ethical guidelines from the Council for Research in the Humanities and Social Sciences (1996) guided the authors through the research process. The ethical considerations were important since the participants had cognitive problems which affected their understanding of information. The research ethics standard of informed consent was achieved through an easy-to-read read letter, which included information and a request for permission to phone the person. The seven occupational therapists forwarded the letter to potential participants. At the interview, the participants also received written information, in easy-to-read form,

Table II. Cognitive assistive devices used by the participants

Handi	
Time Rule	
Weekly schedule	

about the purpose of the study and the right to withdraw from the study. Verbal information was also given in a concrete manner to facilitate understanding of the information. The standard of confidentiality was established in that the participants' names were altered and quotations that could jeopardize anonymity were not used. Guardians were requested to give written consent for the participants younger than 18 years of age.

Data collection

A semi-structured interview guide with concrete open-ended questions was designed (Kvale, 1997). The guide consisted of four concrete questions with follow-up questions. The questions were organized in a logical time perspective where the participants' experience of participation over a period of time was of interest. The questions started with the present experiences of using CAD, asking 'Tell me about your CAD' and 'What do you do if you need help with your CAD?' Then, they moved on to ask about experiences before the CAD was prescribed, asking 'How was it before, when you didn't have a CAD?' and ending with how the participants regarded the future in relation to using the CAD, asking 'How do you think you will use your CAD in the future?' The guide was developed to help the participants to remember and describe their experiences. They were asked to talk about the CAD. During the interview, the participants were also asked to demonstrate how they used their CAD. The interview started with demographic questions about the participant's age, living situation and work or school. At the end of the interview, the participants were invited to give more

information about their CAD and to ask the interviewer about any points that had been raised during the interview. The length of the interview varied between 34 and 60 minutes (mean 44 minutes). Validity during the interviews was obtained since the information that was given was checked continually with the interviewees (Kvale, 1997). The interviews were conducted at a time and place convenient to each participant such as at a habilitation centre, in the participants' home or workplace. One of the participants requested the attendance of a relative at the interview. One other participant wanted the prescribing occupational therapist to attend the interview. These two participants wanted emotional support to help them feel comfortable in the unfamiliar situation. The participants accepted that the interviews would be recorded digitally.

Data analysis

A qualitative approach was chosen since the purpose of the study was to describe experiences in a specific area such as CAD in daily activities. Since the intention was to give descriptions, the procedure described by Malterud (1993, 2009) was used which implies four steps in the analysis, similar to the strategies described by Giorgi (1985).

The interviews were transcribed verbatim to obtain raw data. In the first step of the analysis, to gain a general impression, all the material was read through to get an overview of the interviews. Short notes were made of points that were of particular relevance to the purpose of the study. The second step included the discrimination of meaning units. Every interview transcript was read through to identify meaning units that were connected to the purpose. From this coding process four themes emerged during step three, based on the content of the meaning units. The themes were labelled as the usefulness of CAD, pattern of activities, effect on roles and health and social barriers. Further, the coded material was read to summarize, condense and reduce the content into 12 categories related to each theme (Figure 1). In the last step, quotations from the participants were chosen to illustrate the different categories. The participants' own words were often used in an effort to capture the authenticity of their experiences.

The second author assisted the first author during the analysis. Themes and categories were repeatedly compared with data to ensure that they were based on the interview transcripts. Consensus was reached between the authors regarding the themes and categories. This was accomplished by continuous discussions

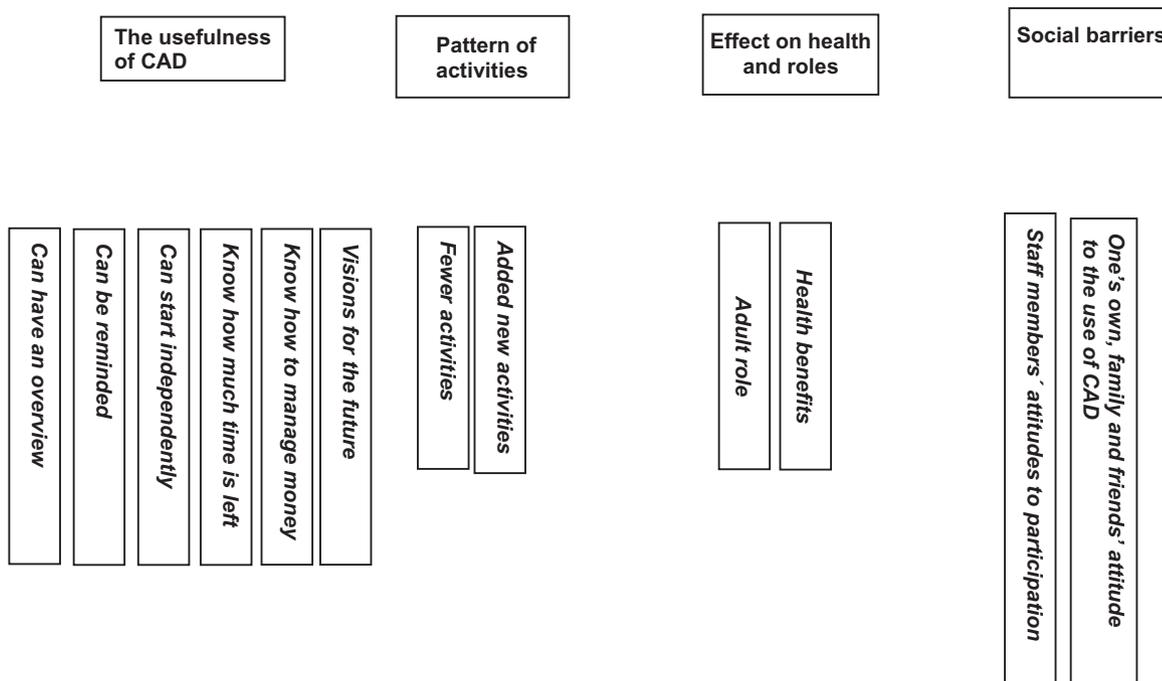


Figure 1 Four themes and categories describing experiences of participation when using cognitive assistive devices (CAD)

concerning plausible interpretations of data. To establish confirmability, the first author's experiences and reflections when performing the interviews were discussed during the analysis process with the co-author. To increase the credibility of the study, the authors discussed the analysis with skilled colleagues at the faculty (Krefting, 1991).

Results

The usefulness of CAD

The majority of the participants feel that the CAD changes their opportunities in daily life. They participate more in the activities they want to or have to perform.

'Now I am reminded in a better way. The Handi peeps and tells me instead of a nagging mom or a nagging staff member.'

One of the participants feels that the CAD has caused minor changes in her activities. She has been prescribed both a Time Rule and a Handi. At the time of the interview, she was only using the Time Rule. She prefers to ask her mother for help instead of getting information from the Handi.

A number of participants use their CAD in all areas of life: to take care of themselves, at work or school and while performing leisure activities. Most participants use CAD in all environments. Two of the participants only use the CAD at home. The participants use the CAD in different ways. Some of the participants use the CAD to be sure of what day, date and month it is.

'I can look at the day and the date.'

One of the participants describes how it was before.

'What will happen, what is one going to do? Before, I didn't know what was going to happen to me.'

Several participants say that the CAD increases their opportunities to find out for themselves what is going to happen, and they now *have an overview* of the activities they would like to perform. Iris, who has both a Handi and a weekly schedule, describes it like this:

'It's good to get an overview, and then it won't be such a mess in my head. Yes I don't know, but I see I don't plan too much on the same day.'

It is also important for the participants to be able to check that the activity, for example a doctor's appointment and planned dates with friends do not clash.

'So then I don't double book. Because I normally use my Handi and look so that I don't accidentally say too much.'

Being reminded and knowing when an activity begins is important for all participants. Participation shows itself as their ability to initiate activities and their independence from others in deciding what must be done and when.

'I am very grateful that I have got this, actually. And that is my Handi, which reminds me now.'

For one of the participants, participation is greatest when she is given support to *start activities independently*, for example different morning and evening routines.

'That I get help with them means I can start different things by my self.'

For a number of the participants, participation increases when they *know how much time is left* until the next activity.

'I usually see how many minutes are left ... time goes quicker.'

Another area of use is to know how much time one has to do certain things, for example to get ready in the morning and get to school or work on time.

One of the participants uses the Handi to *manage money*. She wants to keep track of how much money to pay when she does her shopping. She used to have problems knowing the value of the notes, how much change she should receive while shopping and how many things she could afford to buy.

'How many times have I had to return things? But now I am not in that situation anymore.'

Participants have different *visions for the future* about how they will use the CAD. Half of the participants believe that they will use the CAD, and one person says that it will continue to be essential.

'Can't do without it.'

Half of the participants are unsure. Some hope that the CAD will not be needed anymore.

'If it gets better maybe I won't need it'

'I need it now but when I'm about 40 then maybe I won't have it anymore'

A few of the participants think the need for the CAD may increase in the future if living demands change and the opportunity for participation is affected.

'Because it gets more difficult when I get a home of my own.'

Pattern of activities

The amounts of everyday activities the respondents perform are on the whole the same as before the CAD were prescribed, and so are the activities they perform.

'I do the same amount of things but I don't nag as much as I did before.'

For one of the participants, the use of the CAD has resulted in her doing *fewer activities* which has increased her participation and given her a better balance between activity and rest. Some of the participants have *added new activities* by using the Handi, for example memory lists which are uploaded onto the Handi to ease participation when shopping. Another example is listening to music uploaded onto the Handi, in order to improve concentration when performing working activities. For some of the participants, new activities were added and these were related to administration of the computer, for example to charge and add activities to the Handi. All the participants charge their Handi by themselves. Participation varies when adding new activities to the Handi. One person does it completely independently, some are helped with everything and most get a small amount of help.

Effect on health and roles

That increased participation and the feeling of control have given *health benefits* is confirmed by most of the participants. They give examples of being stressed and nervous and having physical problems before using the CAD.

'Before I got a little nervous and distracted and things like that and had stomach-ache. It isn't as hard now, actually.'

For some of the participants, the use of a CAD in daily activities have led to a changed role – an *adult role*, from being dependent on others to knowing and making independent decisions.

'Before, I used to say (*with a shrill voice*) Mom do you know what time it is and when I must go?'

The role in relation to staff members at work is also changed as participants no longer need to ask or wait to be told what has to be done and when. One participant says that staff members used to tell her what to do.

'Yes, now you must do the dishes, yes, now you must eat and like that.'

Social barriers

Participation can be limited by the *staff member's attitudes to participation*. One participant describes how staff members do not 'keep their promises' about performing planned activities together, for example going to hockey or football. These activities are not uploaded into the participant's Handi, which makes it difficult for her to remember and point out that she would like to do. Two of the participants mention that they are not permitted to upload their work responsibilities to their Handi even though they upload all home and leisure activities independently. The staff members promise to upload activities but they do not.

'We are not allowed to do it ourselves; they have to do it.'

One participant says that she would like to know which member of staff should help her each week but she does not have access to their schedules. Now she sends an SMS every week to ask who is coming.

That both *one's own family and friends' attitudes to the use of CAD* can limit participation is mentioned by a number of participants. Some choose not to use the CAD when visiting family and friends or in shops. For one participant, the fear of irritating people in the social environment is a barrier.

'It peeps a lot ... then it wakes my brother. ... he becomes sulky.'

One of the participants is convinced that he is not allowed to use the CAD outside his home before he has proved he can manage it all by himself.

'I had to get consent from my mum and her [the prescriber] to use it at school.'

Discussion

The purposive sampling gave a broad variety of experiences concerning age, different forms of housing and activities during daytime, but there is an imbalance regarding gender. Data was collected by interviewing people with intellectual disabilities although this might be difficult because the participants can have problems generalizing, remembering and summarizing (Göransson, 1993, Kylén, 1997; Granlund and Bond, 2000). Some studies show that they also tend to answer 'yes' to questions, no matter what the content of the question is (Sigelman et al., 1981; Matikka and Vesala, 1997). However, other studies show that semi-structured interviews give more reliable answers (Kjellberg, 2002; Arvidsson and Jonsson 2006) and narration is made easier if the methods used support the ability to remember, keep focus and structure in logical sequences (Wennberg, 1996; Lindström and Wennberg, 2004). Arvidsson et al. (2008) support the view that people with mild intellectual disabilities can give nuanced descriptions of their participation in all areas of life. Several strategies for increasing credibility were used (Krefting, 1991). The interviewer had several years of experience and was trained to communicate with people with intellectual disabilities. This facilitated data collection and enhanced the credibility of the study. The interview guide was built up rigorously by concrete questions organized in a logical order concerning the participants' experiences of using CAD. Additionally, the participants were prompted to show how they used the CAD in practice.

Some of the participants were more talkative than other. Nevertheless, all the interviews gave valuable information. Two participants wanted to be accompanied by an occupational therapist or a relative. This implied verbal support on a few occasions after the participants had requested it. Anyhow, their presence cannot be neglected but is considered as having only a minor influence on the interviews.

The study's point of departure is the users' experiences of participation when using CAD. Self-rated participation, i.e. reported by the subject is significant when measuring the outcome of interventions in occupational therapy (Townsend, 2002; Kielhofner, 2008). Granlund and Björk-Åkesson (2005) point out the

importance of using self-rated participation for people with mild intellectual disabilities when evaluating interventions.

Using only interviews can be considered as a limitation. One way to increase the study's credibility could have been to observe in real-life situations when the participants used their CAD when performing activities. However, the present study should be considered as a starting point to improve and deepen the knowledge of using CAD and how it may influence participation. Further research in this area could also include a focus group with users with several sessions focusing on experiences of CAD. This will probably provide new perspectives to the use of CAD.

The majority of the participants describe an increased participation in daily activities through using CAD. Molin's (2004) analysis of participation includes components such as taking part, being included and engaged in an area of life, being accepted and having access to needed resources. The participants in the present study call attention to the necessity of having access to needed resources, i.e. CAD. This can be regarded as a prerequisite for what Molin (2004) describes as taking part and being included. Thus, the accessibility of CAD is of importance for realizing the Act concerning Support and Service for Persons with Certain Functional Impairments (LSS) (SFS 1993: 387) in practice for occupational therapists.

The participants say that they do not perform more activities but they do perform their activities more independently, for example they start activities by themselves and organize their day and week. They think they have a greater control of which activities they perform and by that they become more independent. Arvidsson and Jonsson (2006) found in their study that autonomy and independence were separated from each other. There are similarities between how participation is defined in the present study and how Arvidsson and Jonsson define autonomy, i.e. the right to decide matters concerning one own life. That independence and control increased using CAD is verified by Doxner and Kogner (2004) who interviewed relatives of people with intellectual disabilities who had been prescribed time devices.

The participants' descriptions of CAD functioning as compensation correspond well with the literature (Granlund, 1996; Lindström and Wennberg, 2004; Katz, 2005). The descriptions of the support they received from the CAD in performing everyday

activities are often about being reminded, getting an overview and getting help with planning. That corresponds well with the few studies about the target group's use of CAD in everyday activities (Doxner and Kogner, 2004; Arvidsson and Jonsson, 2006; Gatu, 2007).

The participants use the CAD in several life situations such as leisure, working situations and household tasks. This is understandable because the CAD compensates for their cognitive impairment, especially in relation to time perception.

The participants' description of a positive effect on health is interesting and is supported by occupational therapy literature (Townsend, 2002; Swedish Association of Occupational Therapists, 2005; Kielhofner, 2008). Townsend (2002) says that health is influenced by what people do and how meaningful it is to the person. Health is also connected to the possibility of choosing and having control in everyday activities. The participants' descriptions of a changed role in relation to relatives and staff are interesting. The adult role for the participants has been emphasized when using the CAD. This shows how aids such as compensating assistive devices could change roles too.

However, some reported that there are social barriers in participation when using the CAD, especially regarding staff members and families attitudes. This raises questions about the need for information and education in the immediate environment (Scherer, 2005; Arvidsson and Jonsson, 2006; Arvidsson et al., 2008) as well as questions about power and putting the client in the centre (SFS, 1993: 387; SFS, 2001: 453; Townsend, 2002; Kielhofner, 2008). This is a challenge for occupational therapists to handle in a professional manner.

Conclusion

Using CAD enabled participation and resulted in health benefits. However, the participants own attitudes and attitudes in the social environment sometimes hindered the use of CAD. Thus, it is of importance that occupational therapists continuously follow up the use of CAD and its influence on participation in daily life. Since CAD is a growing area of practice, it is important to further investigate how it can influence participation in daily activities. This is especially needed for clients with intellectual disabilities because they are particularly dependent on physical and social environmental circumstances.

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